

Toward A Germinal Theory of Knowing-Revealing-Humanizing as Expressions of Caring in Cancer Palliative Care

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Received: January 28, 2019, Accepted: March 04, 2019

ABSTRACT

Objective: Survival chances of people with cancer in Nigeria are far worse than those in developed countries. While the chance of finding a lasting solution to cancer in Nigeria is remote, patients living with cancer still need treatment regardless of the terminal outcome, and hence cancer palliative care is necessitated. Caring patterns and expressions differ in diverse contexts. Therefore, this article aimed to present the meanings and expectations of caring and the resulting transformative theory of practice. **Methods:** A descriptive, qualitative inquiry was conducted with a purposive sample of 12 cancer palliative patients, 9 nurses, 3 physicians, and 5 relatives who were approached for an in-depth interview about their conceived meanings and expectations of caring for or being cared for in the cancer palliative unit. **Results:** Cancer palliative care

in Nigeria is best exemplified through the processes/themes of “knowing,” “revealing,” and “humanizing.” The meaning of care and the expectations of the patients and caregivers were grouped into these three overarching processes which then informed the conceptualization of a germinal theory of knowing-revealing-humanizing (TKRH) as expressions of caring in cancer palliative care. **Conclusions:** The application of the KRH practice processes is illustrated as a transformative germinal theory of practice. This TKRH as expressions of caring is transformative and can restore positive meanings in the life-world of persons in the cancer palliative care setting.

Key words: Cancer palliative care, humanizing, knowing, Nigeria, transformative theory

Introduction

Human care is a universal phenomenon.^[1] The capacity to care and the need to be cared for is part of human nature. Fry, a caring scholar, has described caring as a way of being

in the world^[2,3] and tracked her thoughts about caring to the work of Heidegger (1927/2011).^[4] Interestingly, Tronto^[5] in 2014 shed more light on the meaning of care as those

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Cite this article as: Nwozichi CU. Toward A Germinal Theory of Knowing-Revealing-Humanizing as Expressions of Caring in Cancer Palliative Care. *Asia Pac J Oncol Nurs* 2019;6:269-76.

Access this article online

Quick Response Code:



Website: www.apjon.org

DOI:
10.4103/apjon.apjon_9_19

activities “that we do to maintain, continue, and repair our ‘world’ so we can live in it as well as possible” (p. 33). However, the pattern by which persons express caring and its meanings is diverse across cultures.^[6]

Palliative care is the attention and care delivered to persons living with serious or life-threatening health issues, in order to relieve their sufferings and enhance their quality of life. Ferrell *et al.*^[7] and Temel *et al.*^[8] have advocated the integration of palliative care services into standard oncology care. Cancer is an important source of morbidity and death globally^[9] and has become a challenge to the health of the public, especially in Nigeria.^[10] The dramatic rise in cancer incidence has influenced Nigerian culture in diverse ways.^[11]

Cancer patients are victims of progressive disease and daily life struggles that shape their experiences before and during hospitalization.^[12] According to reported evidence, there are approximately 102,100 new cases of cancer and a mortality rate of about 71,600 deaths annually in Nigeria, and Nigerians face a 10.4% risk of having cancer before the age of 75 years.^[13] This situation is compounded by the evidence that certain cultural beliefs and values make cancer patients approach the health institutions very late when all traditional treatments have failed to cure their illnesses.^[14] Moreover, the World Poverty Clock has recently declared that the oil-rich Nigeria outpaced India in May 2018 to emerge as the country with the world’s highest number of people (87 million) living in high poverty (living on <\$1.90 a day), in comparison with India’s 73 million people.^[15]

Survival of people with cancer in Nigeria is far worse than that observed in high-income countries, owing to late presentation of cases,^[16] a limited number of oncology (medical and nursing) specialists, lack of equipment and other resources, and extreme poverty.^[17] Although advocacy for a multidisciplinary approach to the fight against cancer and the care of the afflicted ones is ongoing, the roles of the Nigerian nurses in the fight against cancer have been underreported and underrecognized.^[10] While the chances of finding a lasting solution to cancer in Nigeria are remote, patients living with cancer need treatment regardless of the terminal outcome, and hence cancer palliative care is necessitated. However, palliative care for cancer patients in Nigeria is not yet well established;^[18] there is limited literature about what constitutes caring and the meanings attributed to caring in the Nigerian cancer palliative care context.

Caring connotes a variety of meanings. Individuals view caring from their own context and therefore, a universal definition may not be possible. Care meanings, expressions, and patterns vary among cultures, but

there is a lack of Nigeria-based study about caring in nursing, specifically, in the context of palliative care for cancer patients. The complexity of defining caring in cancer palliative care should be viewed from the perspectives of caregivers and care receivers. By doing so, we can understand the essence of our being that we can formulate our own meanings of caring that are harmonious and congruent within our cultural contexts. Therefore, the purpose of this article was to present the meanings and expectations of caring and the resulting transformative theory of practice for persons living with cancer in Nigeria. This study also aimed to develop an understanding of the concept of caring in the Nigerian cultural context. The analysis of data adopted a humanistic perspective.

Theoretical assumptions

The following theoretical assumptions of this article are derived from the theoretical perspectives of caring theorists such as Boykin and Schoenhofer’s theory of nursing as caring,^[19] Rozzano Locsin’s Theory of Technological competency as caring in Nursing,^[20] and Jane Watson’s theory of transpersonal caring.^[21]

1. All persons in the palliative care settings are human beings in the first place and only secondly either a caregiver or care receiver
2. All persons are caring
3. All persons are always whole and do not need to be fixed or measured by mathematical calculations
4. Everybody has a perspective of truth and the world; and
5. Caring is enabling a person to re-discover, re-value, and re-appreciate self as a human person.

Methods

The philosophical viewpoint of this inquiry is derived from Heidegger’s (1927/2011) concept of the human person, underpinning the understanding of the being of the person as a dynamic, unpredictable, multidimensional, and uniquely whole, and follows the interpretive paradigm.^[4] The researcher, being a nurse researcher, co-created the data from the perspectives of the participants. After obtaining approval from the health-care institution in Nigeria, which is a cancer referral center, and informed consent from the participants, a purposive sample comprising 12 cancer palliative patients, nine nurses, three physicians, and five relatives was identified and respondents were approached face to face for an in-depth interview about their experiences of “caring for” or “being cared for” in the cancer palliative unit. The interviews lasted between 40 and 60 min in the participants’ preferred location within the unit. Nonparticipants were not present during the interview sessions.

Data collection

The sample size of this study was dependent on data saturation, as Streubert and Carpenter^[22] suggest that sample size in a purely qualitative study is determined when saturation has been reached. The author, a nurse researcher, utilized an interview guide to conduct the interview containing questions such as: what does care mean to you from your experience here? Can you think of any story that portrays your perception of the ideal meaning of caring? Tell me about a time when you felt good about an interaction with a patient (for care providers) or with a health-care provider (for patients). The basic demographic information of the participants was obtained after each interview. The interview was conducted once and was recorded using a digital recorder, and notes were taken simultaneously to summarize nonverbal observations during the interview. Participants were informed that the study is voluntary and that they have the full right to withdraw at any point without any consequences whatsoever. Prior to data collection, the researcher had been trained and is experienced in qualitative nursing research studies.

Data analysis

The recorded interviews were then translated and transcribed verbatim. After data transcription, the researcher listened to the audio recordings separately and compared them with the transcribed texts to ascertain the accuracy, and necessary corrections were made where necessary through participant checking. Data were coded using Nvivo 7 (QSR international, Melbourne, Australia) and were classified as related to the phenomenon of inquiry. Each transcript was read several times, line by line. Descriptors from the words of the participants that describe the phenomenon of interest were identified, to initially generate codes and categories. Data categories were reviewed to discover recurrent patterns of meanings

and conceptions of caring. The investigator then identified major themes and constitutive patterns as they emerged. A theoretical framework was formulated to provide a clearer understanding of the phenomenon of inquiry. The four aspects of trustworthiness (credibility, transferability, dependability, and conformability) proposed by Lincoln and Guba^[23] were adopted to ensure rigor.

Results

Data analysis yielded three major themes, 13 categories, and 48 verbal expressions as presented in Table 1.

Cancer palliative care in Nigeria is best exemplified through the processes of knowing, revealing, and humanizing (KRH). Each care expectation and meaning was grouped into these three overarching KRH processes. The findings of this study reveal that caring was expressed in a broad range of patterns and has a plethora of meanings among cancer palliative care patients, relatives, and health-care professionals.

Knowing [Figure 1] in this model is illustrated as cultural knowing, responsive sensing, silence as an expression of caring, and technological knowing. Majority of the expressions and meanings address the essence of revealing [Table 1]. Revealing in this instance connotes immersing oneself into the life of others in order to reveal concerns that are concealed or not readily expressed by the other. Revealing is achieved through four fundamental processes [Figure 1], namely witnessing the lived experiences, expression of authenticity, engaging in the world of others, and mutual discovery.

The final theme/process is humanizing expressed as intentional caring, re-discovering human persons, liberating self and others, appreciating wholeness of persons, and enabling transcendence.

The conceptualization of this theory was informed by the responses of the participants and viewed from a

Table 1: Expectations and meanings of caring with verbal expressions

Expectations and meanings of caring	Verbal expressions
Knowing	Knowing the patient's name, communicating through touch, cultural inquiry (cultural knowing), expression of interest, silence as an expression of caring, family involvement, observing patient's interaction with self and family, responsible use of technology, responsive sensing, bringing home to the hospital, interprofessional harmony
Revealing	Recounting life before illness, participating in prayer sessions with patients and family regardless of religion, accepting death as part of life, active engagement, expressing interest in the patient's fears, checking on patient's outside duty hours, sharing in patient's regrets and hopes, patient's comfort (pain management) as a priority, addressing family disputes, reconnecting patient with family, caring for the family means caring for the patient, allowing patients to express their thoughts and feelings, continued communication with family after patient's death, expression of interest about patient's expectation after death, expression of a deeper interest in the worries and concerns of the other, expression of authenticity, accompany the patient in a relational and transformative way, engaging in the world of others, mutual learning and discovery, exploration of patient's lived experience, mutual acceptance
Humanizing	Making oneself available, patient's choice counts, "Chief Ade instead of the patient with colon cancer," appreciating nature, human dignity, living the meaning of one's own life, appreciation of death, intentional caring, we are all human beings regardless of health status, patient's preference is more important than protocols, all human beings are equal, everyone is unique, expression of sincerity, helping patient to re-discover and re-appreciate self as a person, subjectivity of life, enabling transcendence

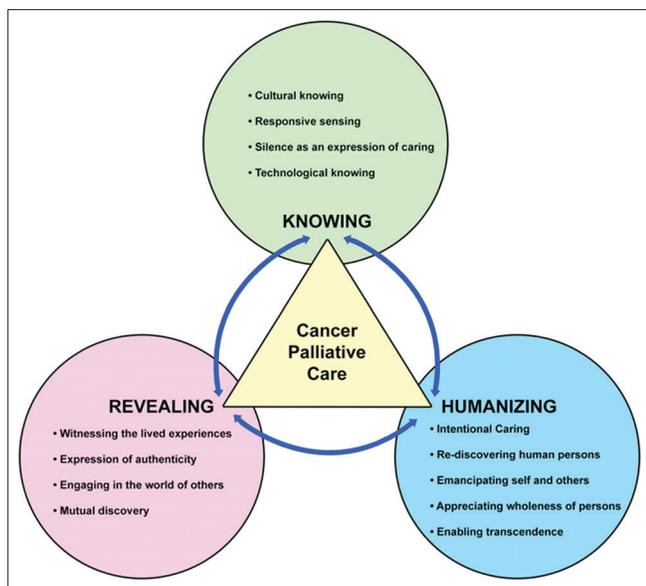


Figure 1: Knowing-revealing-humanizing processes

humanistic perspective. The verbal expressions indicated in Table 1 are the caring expressions, expectations, and meanings derived from the participants' responses. The analysis of participants' responses was not discriminated. The three cancer palliative care processes are continuous and integrative, with neither a starting point nor an ending [Figure 2]. This model portrays that cancer palliative care is a holistic phenomenon and the focus of care is the wholeness of persons.

Discussion

The term patient is used in this article to describe a person who is entitled to health care as a human being. It is, however, recognized that the term patient is often used to represent a person receiving medical services with a dehumanizing undercurrent of a passive receptor or an object of care rather than a co-participant. The rudimentary goal of palliative care is the amelioration of pain and suffering. This study attempted to explore what caring means to cancer patients, relatives, and caregivers working on the palliative care units and develop a germinal theory that will have a direct effect on palliative care in Nigeria. The findings of this study revealed that palliative care must also address how patients live, not just how they die. Because a lasting solution for cancer in Nigeria is not yet established, paying attention to palliative care services is hereby justified.

“Knowing” as an expression of caring in palliative care

Knowing was identified as an important theme in this study. Participants described different approaches to knowing that signifies an expression of caring. Patients, relatives, and caregivers pointed out that addressing patients

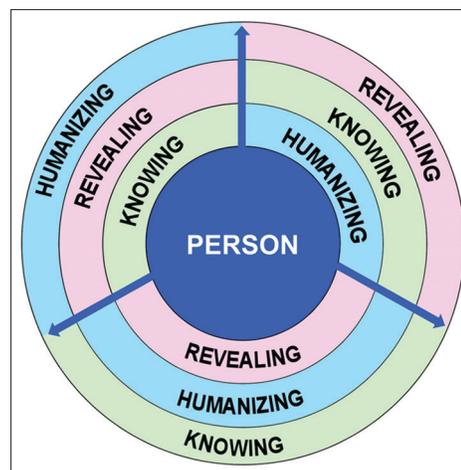


Figure 2: The integrality of the knowing-revealing-humanizing processes

by their names and titles is a way to open more possibilities of caring. As rightly explained by McKenzie,^[24] knowing the patient's name and making efforts to pronounce it correctly is essential to building good connection and a trusting relationship between caregivers and the patient and family members. This finding is quite important in the Nigerian context because Nigerians are very proud of titles^[25] and they always desire to be addressed with their titles, even when they need health-care services, as a form of respect.^[25] Addressing patients with their titles and names, instead of bed number of diagnosis, is an important expression of caring. The role of touch in palliative care has long been explored in the literature. For example, over two decades ago, Sims^[26] reported that touch is a powerful way of facilitating communication and enhancing psychological and physical comfort. More recently, Senderovich *et al.*^[27] introduced a therapeutic touch program in palliative care and reported that therapeutic touch yielded relaxation and showed potential value as an adjunct therapy to assist patients in relaxing and coping with prevailing realities. This study found that touch was a means to know patients completely. The touch reported in this study is beyond the touching associated with a procedure or task but a touch that is intentional and often brings about smooth interaction between patients and their caregivers. An interesting mode of knowing in palliative care is silence which was presented as an expression of caring. This corroborates the findings of Back *et al.*^[28] who referred to it as compassionate silence. Other scholars have addressed the role of silence in knowing patients in palliative care.^[29] More recently, Sapeta and Simões^[30] described silence in palliative care as the “primacy of human presence” (p. 161). Sapeta and Simões further suggested that, although silence is a means of knowing and communicating, it should not be used to shy away from difficult questions.^[30] What matters most is the ability to

empathize with the silence of the patient, an active presence, to transmit a sincere understanding of what he/she means. Durieux *et al.*^[31] referred to this pattern as “connectional silence” (p. 1). Participants in this study reported that silence is more preferred than empty sets of words; however, silence in this instance goes beyond withholding speech.

In general, the present study identified four modes of knowing [Figure 2] – cultural knowing, responsive sensing, silence as an expression of caring (compassionate silence), and technological knowing. Previous studies have supported these findings. It is only through knowing that providers can render caring that meets the essential and existential needs of the patient, and more truly immerse themselves in the patients’ world.^[32] Technological knowing is best exemplified by what Locsin^[33] described as the co-existence of caring and technology whereby technology is used to know persons more fully as human persons and not objects of care. Responsive sensing as a mode of knowing is described as a position whereby health-care providers advance caring relationships and communication by functioning as a team with patients and relatives in a co-creative process. Bergdahl *et al.*^[34] in their study posited that the co-creative process of responsive sensing could improve the dying patients’, the relatives’, and the families’ possibilities to attain essential goals in palliative care. Cultural knowing or cultural inquiry is an approach that familiarizes health-care professionals with the cultural identity and uniqueness of the persons being cared for. Cultural knowing is the acknowledgment of one’s state of mind and presumptions in contrast to others. Therefore, understanding and tolerating the sociocultural, religious, and moral dimensions of a patient’s care are important determinants of successful care results.^[35] Interestingly, cultural knowing is exemplified as bringing home to the hospital, implying that patients want the hospital environment to have some resemblance of their homes. Unfortunately, the Nigerian public hospital wards, mostly characterized by the famous open multibed wards, are experiencing critical challenges in synchronizing formal and informal activities of the patients within the hospital spaces.^[36] The patients mostly accompanied by their families find it difficult to find their daily activities fit into the hospital environment.

“Revealing” as an expression of caring

Oftentimes, palliative patients and their families have needs that are not adequately addressed. For health-care professionals, including nurses, being able to address patients’ care needs can be a challenge.^[37] Due to certain factors, patients tend to conceal some of their important needs. It is exigent for nurses and other health-care personnel to improve the quality of interaction. According to Barry *et al.*,^[38] the most important attribute of patient-centered

care is the active engagement of patients. Caregivers need to start out with the right framework which is to incorporate in the person’s whole life. Patients’ needs have been assessed by clinician researchers, and there is no general consensus about what constitutes the needs of patients. This is compounded especially by patients’ needs which do not fall under the health-care domain.^[39] Revealing the needs of patients is required to guide their plan of care because palliative care patients and relatives do not freely communicate their concerns to clinicians.^[40] Even when patients communicate their concerns, oftentimes, they conceal some important psychosocial concerns that may have a significant impact on their well-being. Others have the impression that clinicians do not want to address such issues.^[40] Weighty evidence points to the damaging effects of inadequately meeting patients’ total nursing needs.^[41] The collaborative relationships are opportunities to attract caring possibilities. Therefore, interactions are directed toward understanding the person as a person, which reveals, defines, or explores other ways of nurturing the person’s wholeness, well-being, and more-being.

Findings of the present study identified various modes of revealing as an expression of caring. Such patterns include witnessing the lived experiences, expression of authenticity, engaging in the world of others, and mutual discovery. Witnessing the lived experience involves enabling the patient to recount his or her life before the illness and explore hopes for the future, and expressing interest in the patient’s fears. To clarify this, Black *et al.*^[42] opined that engaging with and understanding the perspectives of patients and their family is critical in palliative care. Witnessing the “patient’s lived experience” can facilitate the provision of care that is responsive and adaptive to individual palliative patient need.^[42] The present study further revealed that caring is characterized by authenticity. Seno identified that patients and family in palliative care have unmet needs because health-care professionals are unprepared to be authentic.^[43] Seno further described this attribute as authentic “being-with”^[43] (p. 377). The present study found authenticity to be an essential mode of revealing in cancer palliative care. Authenticity is expressed as checking on patients’ outside duty hours, expression of interest about patients’ expectations after death, and being frank during discussions about death. In a previously mentioned study,^[43] each nurse described acceptance of death as part of life; therefore, they were calm and quiet, open, ready, nonjudgmental, and entirely available for the patient and family. The authors further reported that health-care professionals comported themselves toward dying patients and family members in such a way that they cleared the way for people to be themselves, the

way they are.^[43] These are genuine representations of the characteristics and meanings of caring in the present study. Authenticity is described as a core attitude of health-care professionals^[44] and a philosophy^[45] in palliative care.

Another pattern of revealing is through engaging in the world of others. Showing genuine concern about family members is considered an act of caring. Engaging in the world of others necessitates accompanying the patient and family in a relational and transformative way. The patient as a person is revealed, and patient–caregiver interactions yield higher possibilities for growth and more-being. The last mode of revealing is mutual discovery, which is otherwise known as caring disclosure. This pattern facilitates the revealing of self to the other in order to strengthen care connectedness. Human beings often hide their inner thoughts and feelings because they are concerned if other people will accept them. Mutual discovery makes the outer world as similar to the inner world as possible. This can be achieved through the presentation of narratives to the familiar other.^[46]

“Humanizing” as an expression of caring

Provider–patient interaction magnifies the patient’s humanness, thereby helping him or her to re-discover, re-value, and re-appreciate self as a human person. Therefore, when palliative care is humanized, the patient is no longer just a recipient of nursing care but a co-actor and co-participant in the preservation of humanism through caring. The participants in this study expressed that the ultimate goal of caring in palliative care is to preserve human dignity and personhood despite the current limitations of illness. In acknowledging that “dignity enhancing” or “dignity-preserving” care for palliative care patients is essential, interventions such as the dignity mode^[47] have been magnified as a potent approach to ensuring a human-centered care, thereby advancing patient autonomy and recognizing the person as a human person. Terminal illnesses such as cancer alter the sense of the self of a person,^[42] compelling him or her to reach an agreement with the self again in the face of uncertainty. Death necessitates humans to re-appreciate and re-value life and thereby move beyond the apparent nothingness and meaninglessness of life.^[48]

The findings of this study revealed five modes of humanizing, namely intentional caring, re-discovering human persons, emancipating self and others, appreciating the wholeness of persons, and enabling transcendence. Intentional caring entails putting human consciousness into action in the preservation of human dignity. Without intentionality, the nurse may be so engrossed in executing tasks and protocols as a matter of necessity that conscious considerations cannot be given to the caring relationship.

Participants in this study realized that intentionality is required to overcome this challenge. A previous study conducted among oncology nurses in a Nigerian setting reported that task-oriented nurses are prone to high stress and burnout inherent in cancer care.^[49] Intentionality was described by Jane Watson^[50] as a framework for transpersonal caring which helps to break any resistance during caregiving. According to Watson,^[50] “when one declares intentionality toward an action, whatever resistance may be within tends to mobilize and dissipate, allowing manifestation of intention to be realized (p. 14) ...and universal energy-field are posited as the foundation of a caring moment, potentiating healing for both practitioner and patient” (p. 12). There must be a conscious commitment to help the patient to grow in what he or she wishes to become. Elements of intentional caring in the present study include making oneself available and addressing patients by names rather than diagnoses or bed or room numbers, which was identified as a usual practice in Nigeria. The loss of the sense of self during cancer diagnosis and palliative care necessitates caregivers to enable the patient to renegotiate his or her identity within the new context of his/her reality. The goal is to make the person feel like a human person and nothing less. Elements of re-discovering human persons from this study include reinforcing that “we are all human beings regardless of health status” and helping the patient to re-appreciate self as a person. Re-discovering self is directly linked to emancipating self and others. The patient is emancipated when all possibilities are explored to provide total comfort and effective pain relief because everybody deserves to be free from pain regardless of dying status. In the context of appreciating the wholeness of persons, while the biomedical/positivist paradigm considers persons as being made up of parts,^[51] humanized caring fosters the wholeness of persons as always complete needing not to be fixed or made whole again.^[52] Elements that constitute the wholeness of persons include appreciating nature, re-appreciating self as a person, and acknowledging that patients’ preferences are more important than protocols.

The final mode of humanizing is enabling transcendence. Transcendence in this study is associated with one’s spirituality and the connectedness between the self and the external world and also the person’s ability to think in a creative and transformative way to appreciate art, nature, universal complex, or spiritual entities. The concept of transcendence has attracted so much attention in the literature since the promulgated theoretical framework of Maslow.^[53] The development of transcendence among palliative patients was also reported by a similar study.^[54] While palliative patients progressively encounter difficulties caused by cancer, they also tend to seek meaning and

purpose in their lives. Although Iwamoto, Yamawaki, and Sato reported that palliative patients experience self-transcendence,^[54] findings of this study reveal that palliative health-care providers serve to enable patients to find the meaning of their existence, attain high functionality, and explore human possibilities through humanized caring. Elements of enabling transcendence in this study include an appreciation of subjectivity of life, living the meaning of one's own life, appreciation of death, and participating in prayer sessions with patients and family regardless of religion.

Conclusion

The human experience is a process of expanding consciousness to maximize the power inherent in a person that advances to a higher level of consciousness.^[55] The integrality of the KRH processes is represented in Figure 2 implying that the processes are nonlinear, and therefore have no starting or ending point. This study identified three critical humanistic processes that exemplify caring for cancer patients in palliative settings. The application of KRH practice process is illustrated as a transformative germinal theory of practice. This theory is transformative and can restore positive meanings in the life-worlds of persons in cancer palliative care setting through caring.

Acknowledgments

The author greatly appreciates the participants of this study for their time and patience.

Financial support and sponsorship

This study was funded by Babcock University, Nigeria, and the Southwest Nigerian Zone of Mandatory Professional Development Program (MCPDP) for Nurses.

Conflicts of interest

There are no conflicts of interest.

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